



## Indiana State Department of Health

### Positive Cystic Fibrosis Newborn Screen – Two Gene Changes

#### What is newborn screening for cystic fibrosis?

Before babies go home from the nursery, they have a small amount of blood taken from their heel to screen for a group of conditions. One of these conditions is **cystic fibrosis**, or CF.

#### My baby's newborn screen was positive for two gene changes. What does this mean?

**Everybody inherits two copies of the CF gene** (one from our mothers and one from our fathers). Sometimes these genes have **changes** (also called mutations) that prevent the gene from working correctly.

In order for a person to have CF, he or she must have two gene changes. **Your baby's newborn screen was positive for two gene changes.** This means that your baby most likely has CF.

#### What are the symptoms of CF?

Every child with CF is different. Some babies will have very few symptoms until they are older. Common symptoms include:

- Difficulty gaining weight
- Thick, greasy stools
- Coughing
- Wheezing

#### What is the treatment for CF?

Although there is no cure for CF, good medical care makes a difference. There are treatments that can help with the symptoms. With early diagnosis and treatment, most children with cystic fibrosis can grow up and live into adulthood.

#### What happens next?

Your doctor will arrange an appointment for your baby at a Cystic Fibrosis Foundation (CFF) accredited center. At this visit, you and your baby will meet with a team of health care providers who specialize in caring for babies with cystic fibrosis. Your baby will be evaluated, and any treatments that are needed will be started.

You may also meet with a genetic counselor to discuss the chance you and your partner have of having other children with CF. Other family members may also have a higher chance of having a child with CF. The genetic counselor will talk about these risks with you.

Babies with CF will need regular visits with their CF team to help manage their treatments. They should still see their pediatrician for regular baby check-ups as well.

#### Where are the CF centers in Indiana?

CF center locations can be obtained by calling the Newborn Screening Program CF Coordinator at the Indiana State Department of Health at (888) 815-0006.

#### Where can I get more information about cystic fibrosis?

- **Cystic Fibrosis Foundation**
  - [www.cff.org](http://www.cff.org)
  - Toll-free (800) 344-4823
- **Indiana State Dept. of Health**
  - Toll-free (888) 815-0006
- **About Special Kids (ASK)**
  - [www.aboutspecialkids.org](http://www.aboutspecialkids.org)
  - Toll-free (800) 964-4746